



**SPINAL CORD**  
COMMISSION

# SPINAL COURIER

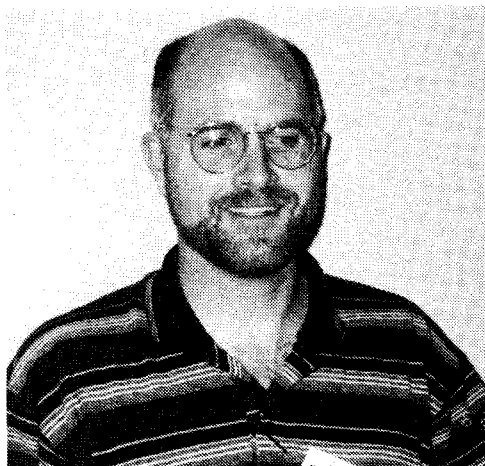
Vol. 9, No. 4

July 1998

## ASCC Welcomes New Medical Director

Dr. Tom Kiser joined the Arkansas Spinal Cord Commission as our new Medical Director in March. The Commission members and staff are very excited to have a physiatrist with Dr. Kiser's sincere interest in spinal cord disabilities working with us.

In addition to his part time (four hours per week) Medical Director position, Dr. Kiser is a very busy guy! He is an Assistant Professor in the Department of Physical Medicine and Rehabilitation at UAMS. In that capacity, he sees patients at Baptist Rehabilitation Institute. Dr. Kiser is on staff at Hot Springs Rehabilitation Center serving as physician on the Spinal Cord Injury Service and in the new monthly SCI Outpatient Clinic. He is also the physician consultant on the Commission's CAPPS (Consumer Action to Prevent Pressure Sores) project.



In his "spare time," Dr. Kiser is completing his Masters of Public Health degree in Biostatistics and Epidemiology through the Tulane University School of Public Health. You can see why we feel so fortunate to have him on board!

Dr. Kiser, who hails from Missouri, completed his undergrad-

uate degree at the Naval Academy in Annapolis, Maryland and served in the US Navy as a nuclear submarine engineer before entering Medical School at the University of Missouri. His medical residency brought him to Arkansas and UAMS in 1992. Dr. Kiser and his wife, Dr. Pam Kiser, and their three children Daniel, Samantha and Rebecca live in Little Rock.

With his broad practice, Dr. Kiser is bringing many new ideas and "hands on" perspectives regarding medical care and long term treatment of persons with spinal cord disabilities to the Commission. We look forward to working with him.

Please join the Commission Members and staff in welcoming Tom Kiser, M.D. to ASCC! &

## Entering New Territory

*By Susan Zook*

My son, Charles, sustained his spinal cord injury (SCI) just six weeks before the Spinal Cord Commission's conference in May, so this is new territory for our family. The first surprise at the conference was the big crowd; I did not know that SCI affects so many lives. Attending meetings with an auditorium full of people in wheelchairs gave faces and personalities to the statistic of 10,000 new SCIs each year. Another surprise was that the

speakers came from across the country. There is a national network of specialists and caregivers working with people with spinal cord disabilities to improve life for the physically challenged.

The subject matter of the conference was comprehensive including physical, financial, medical, recreational, emotional and environmental needs of people with spinal cord disabilities. The volume of information in the sessions

was overwhelming; the hand-outs helpful for review. At the end of one session, five social workers focused and commented on my question alone. Before another session, I met OTs and PTs who helped me to better understand Charles' level of injury (C5,6).

The most valuable resource was meeting persons with SCI and their families. I had lunch with one mother and her son whose  
*Continued on pg. 3 - see "New Territory"*

## SPINAL COURIER

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## With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at (501) 296-1788 / (800) 459-1517 / TDD (501) 296-1794 or send your donation to:

AR Spinal Cord Commission  
1501 North University, Suite 470  
Little Rock, AR 72207

### *Donations this quarter from:*

Debbie Dean  
Lani Lollar  
Central Arkansas Chapter,  
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Neuroscience Nurses

*In honor of Dr. Shirley  
McCluer's retirement*  
Mr. & Mrs. Russell Patton II

## SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

### Latex Allergy Website

Dear Editor:

Persons with spina bifida, anyone who has multiple surgeries and health care professionals are at "high risk" for having an allergic reaction to latex — it can even be life threatening due to anaphylaxis! It is very important that anyone with latex allergy avoid contact with products containing latex. While on the internet, I came across a website devoted to latex allergy. The list, *Latex-Free Alternatives for the Home*, is very help-

ful. Also available at this website are mailing lists and other resources. To check this out on the internet for yourself, go to:

**<http://latexallergyhelp.com/tablehom.htm>**

*Lise Kraemer  
Dover, AR*

PS: Readers, copies of *Latex-Free Alternatives for the Home* are available in the Shirley McCluer, M.D. Education and Resource Center on Spinal Cord Injury (formerly the Arkansas Education & Resource Center on SCI). To obtain a copy, call (501) 296-1792 or (800) 459-1517.

## From the Director

I don't make a practice of reading the writing on bathroom walls, but the sign on the inside of the bathroom door at the Dawson Education Cooperative in Arkadelphia, where I was giving a talk last month intrigued me. "*A good teacher takes more than her share of the blame and less than her share of the credit.*" In my mind, I immediately replaced "teacher" with Case Manager, Director, parent, friend, co-worker — the list was endless.

Many of us are quick to share blame when something goes awry, as it often seems to do. We're not so quick to share the credit when there is (finally) success or accomplishment. I think the sign in that bathroom needs to go on my mirror, so I can read and remember it every morning — how about yours?

May was a bittersweet month for me, our conference was a grand success but we lost many folks near and dear to us, including former Commission Member **Sloan Lessley** who died of cancer at the end of the month. Sloan was a mountain man from Calico Rock who entertained us with stories of his many adventures and exploits. The one I always remember is the time at HSRC when, as a new T10 paraplegic, he donned long leg braces and raced another student up nine flights of stairs to the top of the Center. It was quite an accomplishment, and one he still enjoyed 30 years later!

Besides his stories, Sloan will be remembered for his advocacy in making outdoor recreation in Arkansas accessible to wheelchair users. Sloan worked closely with the Game and Fish Commission, the Corp of Engineers and ASCC to design and build accessible fishing piers (the "cowcatcher pier" was his design) around our state and to coordinate fishing derbies for wheelchair users to heighten awareness to these resources. Many Arkansans benefit from Sloan's efforts.

Despite his gruff ways, Sloan Lessley was "one of the good guys." He'll be missed.

*Cheryl L. Vines*

# 1998 Conference



Danny Wooden (left), who won the \$100 drawing for early registration for the conference, receives his check from ASCC Case Manager Annie McKnight (right). Way to go, Danny - it pays to register early!



Alvin Carruth (lower left), the winner of the Quickie Wheelchair, with his wife, Peggy (top left), ASCC Executive Director Cheryl Vines (top right) and Bob Swiney (lower right), Sunrise Medical Rep. Congratulations, Alvin!



Cathy Parsa and Gary Chambers presented "Gary's Story."



John Gould was the Conference Coordinator. Great job, John!



Chris McAllister discussed his experiences with Service Dog, Blue.

## New Territory

Continued from page 1

level of injury is the same as my son's. It was gratifying to get to ask mother-to-mother questions and I was happy to spend some time with a poised, well-adjusted young man whose injury occurred five years before. They even gave me a tour of his new minivan.

Heartfelt appreciation to the Spinal Cord Commission for their well planned, smoothly executed conference. They were already giving us much needed guidance and support in the person of our Case Manager, Martha Henderson. The conference gave us a cram course in living and dealing with SCI. This knowledge gained has given us more confidence to handle new daily challenges. It is just in time, too, because Charles is coming home from rehab this week! Those of us on Charles' team feel that we are initially prepared thanks to the Arkansas Spinal Cord Commission. &

# DANGER!!! It's Hot Outside

As the heart of summer approaches, temperatures are soaring at record breaking rates. These are definitely the "dog days" of summer. Everyone should be aware of the danger of heat stroke and heat exhaustion, especially individuals with spinal cord disabilities. A person with a spinal cord disability is more at risk than most and **the higher the level of injury the greater the danger of heat stroke**. Since most individuals with complete spinal cord disabilities do not sweat below the injury (many tetraplegics cannot even sweat above the injury), body temperature will begin to rise when the outside temperature is over 85 degrees and the humidity is high. This could create serious health risks which could be deadly. So as you are contemplating venturing out into the scorching days of summer, please be aware of the dangers involved and keep the following information in mind:

## Symptoms of Overheating

Most symptoms are vague but often include:

- Headache
- Rapid Pulse Rate

- Weakness
- Fatigue

If these symptoms occur or if the body temperature is over 100 degrees with no reason to suspect fever, **begin treatment at once!!!**

## Treatment

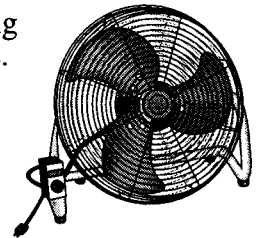
1. Cool the person as quickly as possible.
2. Remove clothes and wet the skin (use wet towels or sheets).
3. Take the person to the emergency room as quickly as possible.
4. Inform the ER personnel of your suspicions regarding heat exhaustion or heat stroke.

Remember, when the body temperature reaches 105 degrees or higher there may be delayed damage to several body organs (kidneys, liver, brain) even after normal temperature returns.

## Prevention

- Avoid temperatures over 85 degrees, especially when the humidity is high.

- Stay in the shade and out of the sun as much as you can.
- Avoid dehydration — drink lots of water.
- Wear loose, light colored clothes.
- Keep skin and clothing damp by using a spray mist bottle of water or place a cold wet towel around your neck.
- Use a fan to circulate the air if no air conditioning is available.
- Minimize your physical activity.



Summer heat is a serious, life threatening problem. Do not take it lightly!!! Your health and life could be in jeopardy.

If you would like more information on this subject, contact the Shirley McCluer, M.D. Education and Resource Center on Spinal Cord Injury. &



## Spina Bifida Camp '98

Forty-nine kids, including **Aaron Combs** of Newport, AR (pictured at left), attended Spina Bifida Camp at Camp Aldersgate in Little Rock, June 21-28. Campers enjoyed fishing, swimming, crafts, music, the annual dance and greeting old friends and meeting new ones.

The Camp is sponsored by Camp Aldersgate, MedCamps of Arkansas, ASCC and Childrens Medical Services. Special thanks for the wonderful picnic goes to **Gary Crockett** and the Spina Bifida

Association of Arkansas and thanks for help with staff training to **Dr. Vicki Stefans, Teri Frewall, Becky Bregy and Kim Scott** of Arkansas Children's Hospital and **David Cossey** of Alliance Home Health. Other donations for camp supplies came from D&S Medical and Mentor Urological Supplies.

Thanks to everyone who helped make the Camp week a great success! &

# Management of Spasticity, Part I

Tom Kiser, M.D., ASCC Medical Director

In my first opportunity to write for the *Spinal Courier*, I would like to address a medical condition I see routinely in patients that come to see me in my SCI clinic, spasticity. Spasticity is a motor disorder that appears to increase the faster an arm or leg is moved and results in increased muscle tone and abnormal movement of that extremity. This is a two part series; Part I discusses what spasticity is and how it can be managed. Part II will discuss the commonly used medications used to help manage it.

## What is Spasticity?

Spasticity is part of the "Upper Motor Neuron Syndrome" that effects the majority of individuals with a spinal cord injury. The lower motor neurons are no longer under the control of the brain or of the upper motor neurons when the brain or spinal cord is damaged. Initially after your injury, your spinal cord was in shock, but when the recovery process started, the lower motor neurons in the spinal cord began to function again. Unfortunately, the lower motor neurons cannot get the information they need to function properly from the brain. The lower motor neurons now respond to input from your muscles and nerves without any inhibitory input from the brain and upper motor neurons of the spinal cord.

As a result, rapid movement or pain signals can cause the lower motor neuron to fire, resulting in a spasm. There is no inhibitory information from the brain to shut it off. The result is a sustained muscle contraction or a spasm. Over time, if you do not stretch and range your muscles and joints, the muscles and joints tighten up and, with rapid movement and pain, the spasms occur

more easily, frequently and your spasticity can grow worse.

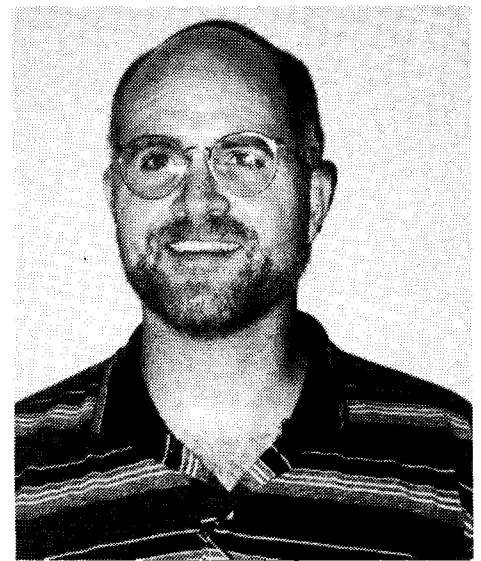
## Spasticity: Friend or Foe?

Your legs jump and draw-up when you try to transfer or lie down. Your back contorts and it is difficult to manage your legs. The slightest movement results in uncontrolled jerks and threatens to throw you out of your wheelchair. What could possibly be good about this?

Spasticity can tip you off to problems or pain below the level of injury. If you have a urinary tract infection, clothing which is too tight or new onset of a pressure ulcer, your spasticity will increase. It also prevents muscle atrophy and, theoretically, could decrease the extent of osteoporosis or bone loss (however, research to date does not support this theory). Some individuals are able to use their spasticity for standing activity and to help with transfers. Spasticity needs to be managed and used to your advantage. Sometimes more extensive physical therapy can help you learn how to manage and use your spasticity to your advantage. The choice is yours, you can control your spasticity or it can control you.

## How to Manage Spasticity?

1. Stretching and range of motion of the back and lower extremities is crucial. It has been shown that after stretching spasticity is decreased for two to three hours. It also prevents the shortening of muscle length over time and joint contractures.
2. Oral medication can decrease spasticity. The four primary medications used to treat spasticity are baclofen (Lioresal), dantrolene (Dantrium), diazepam (Valium) and tizanidine (Zanaflex).



3. Intrathecal medication can be helpful if oral medication is not successful or the side effects are too great. Baclofen is the main medication used, but morphine has also been used successfully.
4. Nerve blocks with phenol or botulinum toxin (Botox) injections can be used to decrease spasticity in a local troublesome area, such as a big toe that sticks up, preventing you from getting your shoes on, or a foot that is pointed downwards and will not straighten out.
5. Surgery can be used to release tendons, cut nerve roots or cut the spinal cord itself to decrease spasticity. They all have different advantages and disadvantages and need to be discussed with your doctor.

In the next issue of the *Spinal Courier*, I will discuss the oral medications used for spasticity caused by a spinal cord injury and look at the benefits and side effects of each one. If you have medical topics you would like me to discuss, call the ASCC office at (800) 459-1517 or 296-1788 and let us know. Or, if you have specific questions, I would be happy to address them. I want this column to be useful to you, and not something to fill up space. &

# Problems with Your Attendant Services?

By Randy Alexander

Are you tired of the excuses that we, as consumers, hear from our service providers: "You should be grateful you live in Arkansas, at least you get some services;" "Well, in some states you wouldn't get this many hours;" "Well, we don't have anyone that could work the hours you need;" "If you just didn't need so much, you wouldn't have to live in this nursing home." As consumers we have heard these excuses, lived through these problems, and still live shackled by the rules that others make for us.

**NO MORE!**  
As consumers  
**let's unite!**

Advocates for People with Disabilities (APD) is a student organization at UALR. The organization is open to all UALR students, but is primarily made up of students with disabilities. As many of us in APD are consumers of in-home health services, we are trying to unite the voices of consumers to improve in-home health services in our state.

We would like to enlist you, the consumer, to **write about the problems you are having** with your attendants, your attendant agencies and other issues you are having with your in-home health services. We are also open to suggestions on ways to solve these problems — after all, **the issue affects all of us**. Concerned that it may be used against you? Don't be. Confidentiality will be handled in one of three ways. First, you

can write to us and not use a name. Secondly, you can use your name, and if any copies are made, it will be blacked out, or you can, in writing, allow us to use your name.

What is APD going to do with these letters? We are working on meeting with our state and local lawmakers to show them that this is a problem — to show them that even though there have been some advances made, they are still too few, too slow and that we are still prisoners of the system.



As an advocate, I have learned that as consumers, **if we unite, we can make a difference**. So, if you are thinking about not writing because you don't think it will make a difference, grab your pen, grab your keyboard, grab whatever you need because it **will** make a difference. With your support, we can unshackle ourselves and open the doors to freedom.

**Remember this, UNITED WE STAND, DIVIDED WE FALL!**

Send your letters, comments or suggestions to:

**Randy Alexander**  
c/o UALR, Disability Support Services  
2801 S. University Ave.  
Little Rock, AR 72204

or you can e-mail me at:  
**randya@aristotle.net**

## New Center Announced for Amputees

An almost immediate response to the diagnosis of a condition or the onset of a disability is the need for accurate, current and timely information. Yet in today's cost-conscious health care environment, answers to even the most basic questions often remain unresolved.

In an effort to address these needs among the over 500,000 Americans who have lost or are missing limbs, the Amputee Coalition of America has established the National Limb Loss Information Center in Knoxville, Tennessee. The Center is a one-of-a-kind resource which provides much needed educational and rehabilitation information and support services to persons facing or who have experienced the loss of a limb.

Callers to NLLIC may request the following types of information from trained information specialists:

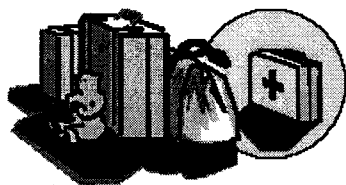
- Answers to questions regarding care options;
- Referrals to health care providers and rehabilitation professionals;
- Reference materials describing prosthetic technology; and
- Direction to local peer visitation training programs.

For more information, or to receive a free copy of the Amputee Coalition of America's national publication *In Motion*, please contact the Amputee Coalition toll-free at (888) **AMP-KNOW (267-5669)** or visit their website at: **<http://www.amputee-coalition.org>**

# Bon Voyage, VISTA Jenni !

Jenni Friedberg served as a VISTA (Volunteers in Service To America) volunteer at the Commission this past year. Many of you spoke to her when you called the Shirley McCluer, M.D. Education and Resource Center to request a book or video, while others met her in the Resource Room at our May conference. If you didn't get to meet her, you can meet her through her work, the ASCC website.

When Jenni came to ASCC, a Spinal Cord Commission website was just an "idea." Thanks to her many hours of research and development, creativity and plain hard work, the ASCC website is a reality! If you have not seen Jenni's handiwork, just check out [www.state.ar.us/ascc](http://www.state.ar.us/ascc)



Jenni has been accepted to Medical School at the Medical Col-

lege of Georgia (her home state) in Augusta, GA, and completed her VISTA affiliation at the Commission at the end of June. We wish her great success in this endeavor and look forward to the day we can say, "We knew Dr. Jenni back when."

This does leave our VISTA volunteer Education & Resource Coordinator position open. If you are interested in learning more about this one year position, contact Cheryl Vines at the ASCC Central office. ♪

## Delta Resource Center Sponsoring a Fishing Derby

Attention fishermen! A fishing derby is scheduled for **July 31, 1998, from 10:00 am until 12:00 pm.** Come and join in the fun and take the opportunity to meet people with disabilities to be more involved in the community. Arkansas Game and Fish will stock 250 pounds of catfish for us at **Oakland Park in Pine Bluff.** We will have surprises for those catching the largest and smallest fish. Bring your fishing poles/rods, bait and chair to sit on, then fish 'til you drop!

For more information, contact the Pine Bluff ASCC office at **870-534-2993.** ♪

# John Sims, Talented Mouthpiece Artist

**John B. Sims**, age 30, of Lake City, AR is a talented mouthpiece artist. Prior to his injury in March 1989, John had mostly done sketching and dabbled with oils. During his rehabilitation in 1993 at Northeast Arkansas Rehab in Jonesboro, John developed his skills using the mouthpiece with the assistance of a Rehab Art Therapist.

His painting subjects range from animals to cartoon characters, each meticulously and accurately depicted on the canvas by means of a brush attached to a device he holds in his mouth. John paints lifelike portraits from photographs, and one of his latest



techniques is 3-D painting (often requiring his painting on several panes of glass to achieve the desired effect) — resulting in a visually exciting creation.

"I spend about six hours each night painting. Art is something I really enjoy doing," John notes. He has created hundreds of paintings and personally signs each one. Many paintings have been sold and are treasured by the owners, while others have been given as gifts.

Recently John held an art show in Indian Mall in Jonesboro with over 200 people viewing his work during the three hour exhibit. He thoroughly enjoyed this opportunity to talk with many individuals about his work. ♪



# New Resources In the Education and Resource Center

The Shirley McCluer, M.D. Education and Resource Center on Spinal Cord Injury has added a number of great items to its collection. If you are interested in checking out any of the resources, please call the Resource Center at (501) 296-1792 or (800) 459-1517. A few of the new resources include:

- “No Barriers” video by Mark Wellman includes segments on extreme sports such as mountain climbing, skiing and hiking. This video contains great footage of people with disabilities doing incredible feats!
- “ASCC 1998 Conference” videos of five sessions at the annual conference in May. These sessions include Mark Wellman’s opening address, the session on Social Security Determination, the session on Service Dogs, Dr. Terry Winkler’s closing address and the alternative health session.
- **Graduating to Independence** was created by the Social Security Administration as a guide for young adults who are trying to make the transition from school to work. This guide includes fact sheets on Social Security, a video tape and a computer program user’s guide.
- **Awakening to Disability: Nothing About Us Without Us** by Karen G. Stone is a first hand account of living with Multiple Sclerosis.
- **ADA Resource Library** includes information on Title II, accessibility requirements for buildings, and even has a special section aimed at businesses trying to meet the ADA requirements.
- “Status of SCI Research” is a series of articles on the anatomy of a spinal cord injury, the effects of SCI on the body, research strategies for repair

and restoration of function and the dilemma of research funding in the US. Originally published in *Paraplegia News*, these articles are great for anyone interested in SCI research. &

## Surf On Over to the ASCC Website

Do you want more information on the Spinal Cord Commission or spinal cord disabilities? A great resource that is now available is the ASCC website. Since its creation and launch, those who have used it have found it to be quite helpful. The site includes descriptions of services ASCC offers, all 28 of our fact sheets, information on the ADA, links to other resources on the web, statistics and much more. So, next time you are surfing the web, don’t forget to look us up at [www.state.ar.us/ascc](http://www.state.ar.us/ascc)

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